

# The Review

June 2015



The Official Magazine of the Cerebral Palsy Society of NZ Inc

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(Cover) Staff Meet New GM  
Standing L-R: Scott, Matt, Michael,  
Harvey, Gilli, Janet, Harper, Shelly  
Sitting: Ross, Amy  
Lying: Mary (dog)

Any opinions, findings, conclusions or recommendations expressed in this publication are those of the authors and do not necessarily reflect the views of the editor or the Cerebral Palsy Society of NZ.

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# Gilli Steps Into The GM Role

Gilli Sinclair will be the Society's new General Manager starting in July. Gilli is a very approachable and friendly lady, as the office staff quickly found out at a team gathering last week. She is very excited about being part of a Society which has strong structures and excellent programmes.

"I'm really looking forward to hearing what members are saying," she said.

Gilli started her working life as a psychiatric nurse but soon moved into management at Carrington and Oakley hospitals focusing on mental health and Child and Health services.

Since then she has had vast experience in designing and developing new services for Health and Education, Social Development and Police and Justice Departments.

Twenty-eight years ago she became one of the founders of the Make-A-Wish Foundation. She has felt wonderful satisfaction when she has helped young, sick people's wishes come true. For example she remembers the foundation helping a young student attend her school ball, despite being hospitalised in the days leading up to the big event. The Make-A-Wish Foundation made her dream come true by not only flying her down to the Ball but also providing a ball gown and after-ball gown. Of course nail and hair styling services were included. All she had to do was hop in the transport provided where her boyfriend waited to escort her to the Ball. Before she joins the Society, Gilli is attending a Make-A-Wish Foundation international board meeting in Frankfurt.

Gilli has also become involved in the



GobabyGo foundation which features on page 9 of this issue of the REVIEW. This is a new concept in NZ which supplies ride-in toys which are adapted to help mobility-challenged children move independently. Twelve cars have already been matched with their, mainly CP, owners.

Obviously Gilli doesn't have too much spare time on her hands but when she does relax she enjoys the company of her family at Muriwai beach. Her family comprises of her husband Jeff and three 20 something children. Nicky works for Youthline, Matt is an artist at University and the other Matt is in the army in Australia. The additional members of the family are three dogs named Ralf, Ziggy and Abby who were rescued from an abusive environment.

Welcome aboard, Gilli

Ross Flood



# Touch Compass Dance Company

New Zealand's pioneering inclusive dance company, Touch Compass, is hitting the road in August with their popular 2014 Acquisitions season. In addition, today they announce a thrilling new line-up of dancers.

The country's only professional, inclusive dance company, Touch Compass works with disabled and non-disabled dancers to create high quality contemporary dance that challenges perceptions about who can dance and what dance is.

According to Touch Compass' Artistic Director, and Acquisitions Curator and Co-choreographer, Catherine Chappell, the choreography draws on the dancers' unique disabilities and, as such, their differences become artistic features.

"We are thrilled to remount Acquisitions with a new look company, which will see the magic from the original choreography come to life with exciting influences from the new Company members," Chappell says.

Acquisitions is a multi-media dance production consisting of two performance works which sit alongside a series of engaging short films.

The first, *Undertide*, explores the experience of living within a body and raises questions around how we experience life from the inside out, supported by intriguing music composed by Clare Cowan.

The second, *Watching Windows*, is a compelling work created by company dancers in collaboration with Catherine Chappell. *Watching Windows* plays with the idea of scale and physical boundaries.

The newly-formed ensemble for



Acquisitions comprises of Georgie Goater, Cameron Lansdown-Goodman, Duncan Armstrong, Alisha McLennan, Joshua Pether, Julie van Renen and Samantha Wood-Rawnsley.

As well as their professional work, Touch Compass dancers undertake community, youth and tutor training classes. They are the only company in the South Pacific providing opportunities for aspiring disabled dancers and choreographers.

Acquisitions will open in Hamilton on 21 August and Wellington on 27 August.

## Season information

Gallagher Theatre, Hamilton

Performance – Friday 21 Aug (7.30pm)

Schools' matinee – Friday 21 August (11am)

Te Whaea Theatre, Wellington

Performances – 27, 28, 29 August (all 7.30pm)

Schools' matinee – 28 August (11am)

Schools' workshop – 28 August (12.30pm)

For more information, images and interviews, please contact: Siobhan Waterhouse or Mr. Fahrenheit Publicity  
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# News From HQ

## Harvey's Departure

As my retirement rapidly approaches it brings a certain amount of reality about writing my last 'News from HQ' article. At the end of July I shall be vacating the GM's role. I have been involved in producing 30 editions of the REVIEW, the first was in March 2007. In that issue I made a commitment 'to make the Society relevant to people with CP and to get them off the bottom rung of the disability ladder', I finished the article with the words 'the journey begins'. I feel I have fulfilled my commitment, and now, this leg of my journey ends and the new GM (Gilli Sinclair) will take the baton.



### Harvey wishes everyone all the best

appoint and remove directors from EAL and the new company to be formed.

I wish to thank you all for your support, especially the staff and the Society's Board, all who work hard on your behalf.

I will still be attending events and be involved with Boccia so our paths are sure to cross again, I certainly hope so.

## New Structure Going Forward

At the Board meeting in May some significant decisions were made about the structure of the Society. Essential Assets Ltd, a company 100% owned by the Society will hold and manage the Society's investment portfolios and property. The Society will form an additional company and provide it with entrepreneurial funding for riskier investment or business building in the hope that in the years ahead it can produce other income streams. This structure will protect the majority of the Society's wealth, allow the Society itself to focus on supporting its members, yet provide scope for future growth. The Board of the Society, which is elected by the membership, will have the power to

## 2015-2016 Year

### The Budget

For the next financial year (begins July 1st), I have been instructed by the Board that we can afford a similar year to last, so expect things to be similar. Obviously we are making room for the growth in membership. We average about 17 new members per month, however we have an attrition rate between years of about 7%, this is after much follow up and work by the team.

### Membership Stand Down Period.

The Board has decided that members who fail to re-join by the date of the AGM (in October), become non-financial members, and if they re-join after that they will have a stand down of 6 months before being able to apply for programmes and grants. See page 8 for details

This is Harvey Brunt, GM, signing out.





# STEPtember Fundraiser

Challenge yourself and your workmates to take 10,000 Steps a day, for 28 days between September 2 - September 30 2015, to raise money for Kiwis living with Cerebral Palsy. It's a win-win situation as participants are motivated to get in shape. On average an office worker takes just 3,000 steps a day so here is your chance to take advantage of the health and well-being aspect of STEPtember. Taking steps is not the only way to reach your goal. An activity conversion table has been created to convert over 40 activities into steps. These include cycling, boxing, yoga, horse riding, boccia and various mainstream team sports. Simply select your activity when you record your steps on the webpage. By the way, manual wheelchair pushing and power wheelchair cruising is among the activities listed.

Here is how it works. Firstly you need to form a team of 4 and register online [www.steptember.org.nz](http://www.steptember.org.nz) to begin your journey and from September 2nd you can track your daily step count on your very own pedometer (which is provided) and record your steps via the website or your smartphone.

The aim is for each team member to take 10,000 steps every day for 28 days during the month of September. That's the equivalent of virtually climbing the highest peak on every continent! Not bad for a month's legwork.

10,000 steps per day is no easy feat, so make every step count by asking your friends, colleagues and family members to sponsor you by making an online donation or you could even hold your own mini fundraiser.

All Cerebral Palsy Society members receive complementary registration for their STEPtember team by using the code



**Lee-Anne puts Warrior Captain Simon Mannering through his paces**

member.

The first team to sign up wins an ecostore gift pack.

When you register you'll receive a STEPtember Kit, which includes a good quality 3D pedometer to count your steps, a STEPtember Handbook and exclusive access to the STEPtember website. STEPtember kits will be sent out from August 1<sup>st</sup>.

Registration is \$25 per adult and \$10 for kids.

New Zealand Warriors Nutritionist Lee-Anne Wan is doing a great job as Ambassador promoting the STEPtember concept. Lee-Anne is best known for hosting the television series "Down size me" and is just starting a new show on Television one entitled "Kiwi Living"

The person behind this fundraiser is Shelly Reilly. This hard working Aussie has just joined the Society as National Manager of the STEPtember project, coming from a Media and Tourism background.

New Zealand is the 10<sup>th</sup> country to take part in this very successful fundraiser so sign up, participate, spread the word and get fit. - Ross Flood



# Harvey Reminisces

It was at a meeting in 1991 that I first became involved with the Society. The meeting was to discuss the introduction of Conductive Education (CE) into NZ. The existing President was retiring at the next AGM and they were canvassing for a replacement, I thought, why not?

At a tumultuous AGM in 1992 I was elected President and would remain so until 2004. Fortunately AGM's quietened down as CE became established in Auckland. With the Ministry of Health moving people out of institutions the Society set up a service arm, and created a company, Focus 2000 Ltd in 1996 which would grow into a sizable business. Over these years Focus 2000 Ltd became the dominant preoccupation and benefits for the members became secondary. Through the business the Society was becoming wealthy, unfortunately this was obscured from the majority of the Society's Board. When this did become apparent there was a push by some of the Board to have this wealth benefit the members. Not surprising, but rather ironic, this was resisted by Focus 2000 and some members of the Society's Board. What ensued was a battle between the two factions. This battle exhausted me and I resigned in 2004. At the tumultuous and skewed AGM in 2005, the battle by those wanting the members to benefit was lost... but not the war. Fortunately some good people were elected to the Board that year who continued the cause. I rejoined the fray at the AGM in 2006 when I was elected Secretary for the Society. Also there was now a Board that was united in using the Society's wealth to assist members. Effectively 2006's AGM marked the victory for the pro-member's faction and the end of the war. Over these



**Harvey shares a joke with daughter Leonie and wife Jos**

stressful years I had often considered what the Society should be doing. I had the opportunity to put these ideas into effect when I resigned as Secretary in February 2007 to accept the position of General Manager.

The Society has grown from a membership in 2003 of 43, based mainly in Auckland, to 1740 member spread throughout the country. There are 7 programmes for the members to use, a social calendar of events, a longitudinal research project for members and our grant system. We now spend over \$1M per year providing benefits for our members. The ethos of 'Freedom & Choice' has been promoted in all that we do.

Here we are now in 2015, I am now 65 and retiring. A new person with new ideas will take the Society forward into a new era. It has been a privilege to have served you all.

Our journey on a parallel road to those of others, it is a special road with 



different vistas. Having a daughter with CP I will remain and look forward to this fascinating journey that we share.

I wish to thank my wife Jocelyn, who has provided the solid base from which I could journey out, my daughter Leonie

for her insights into cerebral palsy and the many friends I have in the Society for their support and ideas, I look forward to maintaining these friendships.

Harvey Brunt wishing you all the best!

## Membership Stand Down Period In Full

We have had many cases where people leave and then re-join a year or two later, just to apply for a grant or what not. As I said in the News from HQ "The Board has decided that members who fail to re-join by the date of the AGM (in October), become non-financial members, and if they re-join after that they will have a stand down of 6 months before being able to apply for programmes and grants", so please don't let your membership slip through the cracks, join for multiple years, it saves time.

In the covering letter that came with this magazine you will see when your membership expires, or when it goes through till (if you have paid for multiple years).

The benefits of membership are the envy of other organisations.

Harvey Brunt



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# Toy Cars Have Multiple Benefits

New Zealand charity GobabyGo NZ aims higher than just making kids smile when it gives them a new BMW electric car. The ride-in toys are adapted to help mobility-challenged children moving independently, and have so far gone to kids with a range of disabilities, primarily cerebral palsy thanks to an excellent information-sharing network among the parents of recipients.

The GobabyGo system was developed by American paediatric researcher Cole Galloway, who discovered that not only might there be therapy benefits to the cars, but there were also considerable social benefits to getting kids mobile in a play environment.

He developed an affordable way to adapt toy cars and made it available to anyone wanting to set up a similar system in their own country, hence the launch of this volunteer-run charity here last year.

GobabyGo NZ CEO Gilli Sinclair says mobility devices can separate a small child from siblings or others in the playground. But a car like this puts them on a level playing field, able to explore boundaries, or simply direct themselves on a family walk alongside bicycle-mounted siblings, instead of always being carried.

"Just being able to play like this helps them develop relationships with peers and siblings and stretch boundaries," she says, "but there are often further benefits as we individually adapt the cars. A child who needs to strengthen their neck may get a headrest-mounted throttle, and we have one boy who hated his hamstring stretches, but doesn't even notice them in his adapted car, as he's too distracted by whizzing about!"

Thirty of the toy BMWs have been donated



**Tauranga recipient Kaleb, age four revs up**

by BMW NZ, and dealerships are getting on board with venues for handovers and technicians to adjust cars if needed. "We've been lucky, Allied Medical supplies items like harnesses, other companies supply cut-rate supplies for the adaptations, we even had Zyber come on board to build a website," Gilli says.

"The challenge now is to find enough sponsors and donors to pay for other costs of getting the cars out, and paying for additional ones, plus developing a national network of coordinators and technicians to serve local areas. Eventually we hope that every child who could benefit from a car, will get one."

The two sizes of GobabyGo BMW cater for kids up to seven years old,

For more information, links to the Facebook page or to apply for a car, and a link to donate via givaelittle – every dollar helps, see [gobabygo.org.nz](http://gobabygo.org.nz).

By Jacqui Madelin

(NB: Since this article was written Gilli has accepted the position of GM with the CP Society.)



# Members In Control On New Website

The Cerebral Palsy Society has created a new website specifically designed for the members.

The newly-designed website can be found at the same address [www.ccerebralpalsy.org.nz](http://www.ccerebralpalsy.org.nz). The website was developed with the focus of giving the members much more control of their own memberships putting them in the driving seat with the member's login dashboard.

Once a login has been activated there are many advantages which give members a lot more power over their membership. From within the dashboard with just a few clicks of the mouse button there is the option of applying for a new membership for first-time members, or existing members can renew their current membership.

Members can also apply for programmes like the getThis&That, getUpAgain, getStructured and the getPhysical programme without having to fill out or post back any forms. The getOutThere programme still requires members to belong to their local Council's Total Mobility Scheme.

Members can add, change or update their personal details like their address and phone numbers. With the address there is the option to have a residential address and a postal address or even a company address. Members can also include their website address if they have one, or even links to their Facebook page to share with other members.

The dashboard allows members to upload photos, and to create a profile of themselves which they can choose



to make available and share with other members online. This is a good feature that allows members to get in contact with each other who may live in the same area, or who even live at the other end of the country.

You can also see your membership status which helps let you know when it may be time to update your membership and also tells you when your vouchers are due to expire so that you can look at reapplying for a programme again.

Under the email tab you can check all the emails that have been sent to you from the society or from other members that may have sent an email from the dashboard.

There are still many things that are going to be added over time, members will soon be able to pay their membership online from within their dashboard. In the coming months members will also be able to register and RSVP for events that they wish to attend.

This is a new look website where members take control.

If you have an email address and would like to create a login you can email [matt@cpsociety.org.nz](mailto:matt@cpsociety.org.nz) who will help you get started.

Matt Slade



# Ministry Of Health Disability Consumer Consortium Feedback

I really enjoy representing the Cerebral Palsy Society at these 6 monthly meetings – not only to hear what the Ministry of Health's (MoH) current projects are – but also to network with all of the other disability organisations who are represented. No surprises that many of the issues that face our members are the same for the wider disability community.

What's on top for the Ministry of Health?

Streamlining contracts for providers – Some providers have multiple contracts with MoH so it is hoped that streamlining will make things easier for all concerned.

Enabling Good Lives (EGL) – Christchurch is more than half way through its demonstration and the Waikato demonstration will start on 1st July. EGL aims to provide more flexibility and choice to people with disabilities and brings together funding from the Ministries of Health, Education and Social Development. The learnings from the New Model, Local Area Co-ordination, Choice in Community Living and EGL will be considered by Government and will hopefully roll out across the country.

Young people in aged care facilities is high on the Ministry's radar – whilst numbers have reduced considerably in the past five years – there are still around 440 people under 65 in aged care facilities.

Funded Family Care is being reviewed – only 195 people are currently being supported. The Ministry is keen to know what the barriers are and why the up take has been so low. Consortium members questioned why the rate of pay is based



**Sally Thomas**

on the minimum wage.

The Equipment and Modification Prioritisation Tool was fully implemented in August 2014. 11,200 people have been assessed of whom 89% received funding. There has been an increased demand for low cost equipment.

Vulnerable Children in Out of Home Care – MoH have concerns that disabled children are treated differently from other children. Legislation and policies are currently being looked at to see how the process can be improved. One of the issues raised by the Consortium was around the 17 year age cut-off from Child Youth and Family which doesn't align with becoming an adult or having a welfare guardian appointed at 18. A public consultation is currently taking place.



How to measure the quality of services? MoH asked Consortium members for feedback on how best to do this. Lots of ideas came forward – the most critical being to directly communicate with the people who receive the services.

Accessible Properties - Andrew Wilson came to talk to us about changes in the social housing scene in New Zealand. This organisation manages 1,070 properties throughout the country. Accessible Properties aim to have social housing close to amenities, shopping etc. and give priority to disabled people to gain access to affordable rentals (affordable equates to around 25% of a person's income).

Workforce feedback – People are having difficulty recruiting males and recognise the importance of training. Consortium members had concerns about the poor pay rates for support staff and the difficulties in retaining staff.

People First - Keeping Safe Feeling Safe Programme – Discussion around recognising abuse and the provision

of training for people with a learning disability on how to keep themselves safe. This programme wants to change the way people are seen and treated across the police and social services when they report bullying, harassment and abuse. Training also includes support for police and judges to assist people with disabilities to disclose.

Health outcomes for disabled people. MoH are concerned about the significantly poorer health of people with disabilities. To help counteract this they are looking at disability training for health providers including doctors, medical specialists and nurses; 'easy read' information and support around using medication properly and managing side effects.

I am thoroughly looking forward to Tony Voss joining me for what will be my last meeting in November. I highly recommend other members think about taking up the opportunity to represent the Cerebral Palsy Society in 2016!

Sally Thomas

## Launch 2014 Report On The Positive Ageing Strategy

On 29 April 2015, Hon Maggie Barry, Minister for Senior Citizens, released the Report on the Positive Ageing Strategy. This is a very important report given the interconnection between disability and ageing.

The report aims to:

- Encourage discussion and debate around what an ageing population might mean for New Zealand, given that older people currently have higher rates of disability than younger age groups
- Encourage organisations (central, local and non-government) to plan for an ageing population.

If you would like to know more, the report is available at: [www.msd.govt.nz](http://www.msd.govt.nz)



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# Global Movement Seeks Local Impact

This year, World CP Day will evolve into a social movement that will empower people with CP, their families and the services that support them, to drive change that makes a difference in their local communities. World CP Day has recently engaged The Matala Line, a communications firm that's devoted exclusively to nonprofits and NGOs, to help craft a "movement building" strategy.

To ensure that World CP Day is truly Global – By addressing the wide range of cultural, logistical, legislative and personal circumstances in which people with CP find themselves in all the various countries of the world, and by providing tools to help them address those circumstances.

To ensure the "Day" is actually the culmination of a year's worth of activity/engagement – Rather than a day of awareness, they are hoping to create a year of advocacy and action that will begin to help ensure that everyone with CP around the world is able to live up to their fullest potential.

One of The Matala Line interviewers, Bill Toliver explained the concept by saying.

"Our core philosophy going into this process has been that we will never have a truly GLOBAL movement on behalf of people with CP, unless we help people to have LOCAL impact everywhere around the world. To create the local impact, we have interviewed doctors from the Tribal Regions of Pakistan to researchers in the US and Australia. We have talked with CP organizations in Nigeria, Turkey, Indonesia, China, Brazil, New Zealand and many, many others around the world.

While we are still in the midst of the process, we have begun to outline a number of general areas in which WCPD



**Bill Toliver talks to Harvey and Ross**

must offer "crowd sourced" content and help. Including, Creating Awareness, Basic Rights, Medical/Therapeutic, Quality of Life, Education and, Contribution/Realisation of potential.

There is much work ahead, as we will be seeking to deliver helpful tools and ideas prior to the launch of World CP Day 7<sup>th</sup> October 2015."

The interviews were certainly thorough as topics raised included discussion on how people with CP are viewed/understood in your culture? How well are they understood and assisted by officials and lawmakers? What opportunities are there for individual people with CP? Perhaps the most intriguing question asked was if you had 5 wishes for people with CP, what would they be?

It will be interesting to see how this concept develops.

Thanks for the info from World CP Day website and Bill Toliver.



# Cerebral Palsy Register For NZ

The Society in the 70's tried to get a register started but it never went passed the feasibility study that was commissioned, It ran out of money and could not source more. Fast forward 40 years and this goal of having a register is about to be achieved. New Zealand will be a partner with the Australian CP Register. The Aussies got their act together in the early 1960's and now have the most prestigious CP Register in the world.

Dr Anna Mackey and Professor Sue Stott from the Auckland Medical School have laid the foundation for the NZ Register. Alexandra Sorhage has been employed to promote and manage the register. Ethics Committee approval and other necessary steps are reaching their conclusion. The register's website will be live before the next issue of the REVIEW, it's all very exciting.

The Society will be encouraging all its members with CP to login and be a part of it. To begin with it will be web based, and when you login in there will be a short survey garnering information about you. It will take from 5-15 minutes, depending on what you can remember. If you remember some fact then you can log back in and update your data. The register is for those



**Standing; Prof Stott, Alexandra Sorhage**  
**Sitting; Amy Hogan, Dr Mackey**  
of all ages and degrees of CP.

If you have any queries then contact Alexandra at [nzcpregister@adhb.govt.nz](mailto:nzcpregister@adhb.govt.nz)

This is an exciting development that will benefit people with CP in the years to come.



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# The Wonders Of Communication Are Explored

Over the past 12 months Talklink has introduced 20 year old Samuel Coffey and 17 year old Shaunica Karkera to the world of assistive technology and its made a massive difference to their lives. Samuel uses a NovaChat device with 2 switches activated by head and hand movement and Shaunica uses an iPad with a Predictable application. Armed with these devices the duo has explored their individual worlds and discovered communication is a wondrous skill to have.

"The iPad is easy for me to use. Also my friends can hear me more clearly. The Predictable program is also simple to use which is good," said Shaunica. She went on to say she is still getting used to the device but it is already making her life easier.

"I can communicate with my friends, the teachers at school and my parents with ease" she said.

She agrees that her new equipment will make her more independent.

Samuel is equally rapt with his newly discovered independence. He wants to take his device home to communicate with family and friends. He is continuously experimenting with phrases such as "How are you? And Goodbye Mum." He has a particular interest in the "All about me" section and chose a range of messages from there like "My name is Sam, I go to school at Wilson School, I am 20 years old, my birthday is on....."

His School Speech Language Therapist's, Susie Mole commented that "each week that Sam has had the device I have seen more of his intelligence shining through his



**Samuel Coffey experiments with phrases**

eyes. It's like he has "woken up." I have got to know him better in the past few months than in all the years prior to him having access to high tech communication. Susie also has notice that Samuel being more assertive than he used to be. "This is a side to Sam that I have not seen before. The experience of successful communication teaches students that they have the right to have their voices heard, and result of that understanding is a new level of assertiveness in them. That's my favourite part of the process!! She said.

Susie went on to predict that "other people in the school will start to view Sam differently now that he has a device and because of that they will talk to him differently and expect him to talk back. I have noticed the looks of curiosity/surprise on the faces of people at school now that Sam has his device mounted onto the chair. I look forward to the time when Sam meets people for the ➡





### **Shaunica Karkera is more confident to start conversations**

first time with his device so that their first impression is of a young man with plenty to say for himself!"

TalkLink's Speech Language Therapist Kate Mentis commented that "Sam is now able to greet new people in a way that is understood by anyone (functional communication) – without a device he is reliant on people who know him to interpret his messages, and we are not always sure if the interpretation is correct. This can be extremely frustrating for both Sam and his communication partner.

As a result of the communication device he is now more independent and can advocate for himself, which is the biggest positive impact in my opinion. He is able to make choices e.g. what music he would like to listen to and let people know what his wants and needs are. I have seen a huge positive change in his demeanour from the first time I met him and am amazed by all the wonderful things he is now able to tell us with his new

communication system.

When commenting on Shaunica, Kate said "The biggest impact of the communication device is that it gives Shaunica the confidence to communicate in situations she otherwise wouldn't have e.g. when meeting someone new, in noisy environments when vocal volume is not sufficient and speech is more difficult and when answering questions in class. She is able to be more social with her peers which has previously been a challenge for Shaunica due to her difficulties with verbal speech. She can now confidently answer questions and participate in class. Without a communication system Shaunica is reluctant to initiate communication in most environments. With the iPad and Predictable app in place she is more confident to start conversations as she is sure her message will be understood and this has a huge positive impact on her social engagement and overall quality of life. Her first challenge with the new device is going to be ordering food from the school tuck shop at lunch time – something she has always wanted to do but was too nervous to do without a communication device

So if you have a need for assistive technology explore all the options at Talklink. You definitely won't regret it. The best way to contact Talklink is go to their website: [www.talklink.org.nz](http://www.talklink.org.nz) and check out the referral forms.



# Cerebral Palsy Through The Lifespan Employment

## MOST COMMON ROLES

1. Disability Organisations i.e. CCS.
2. Government or Health NGO.
3. Self Employment e.g. speaker or own company.
4. Community Group such as Church or Community Youth Centre.
5. Non Disability Roles such as teaching.
6. Combination work e.g. Advisory Boards and Teaching.

## MOST COMMON STRATEGIES WITH EMPLOYERS OR POTENTIAL EMPLOYERS

1. Have a simple explanation of CP on hand
2. Plan for questions on potential CP challenges e.g. approaching Workbridge
3. Know how many hours you can comfortably work and work for short periods
4. Plan out access and disability related costs in advance



## Highlights

- Just over 60% of 155 interviewees to date were looking for, currently in, or had in the past been employed on either a voluntary or paid basis.
- Regardless of CP level few interviewees were able to sustain full time work long term.
- 1: 4 Respondents reported difficulty with WINZ and maintaining government funding.
- Most common reasons for Part Time Work were balancing work expenses, (transport, clothing) WINZ expectations and CP issues such as fatigue.
- Of those not seeking work, the most common reasons are that working costs and fatigue issues outweigh the benefits.
- 70% had experience working in the disability sector and 30% worked primarily or exclusively outside the disability sector.
- Most common work was Part Time in the Disability Sector.
- A majority of interviewees had or expected they would retire earlier than their workmates. Most common reason given was inability to keep up with work demands.
- If you wish to be interviewed for this study or receive further information please contact Amy Hogan (amy@cpsociety.org.nz)





## Mild CP: Employment

Broadly speaking CP Level 1 or 2: walking independently or using walker or sticks.

- Were most likely to work full time for sustained periods.
- 85% lived with minimal or no additional support such as MSD Benefits
- Most common issue at work was 'invisible aspects of CP' e.g. difficulty with hand function for admin tasks (filling out forms or databases) or working at speed to complete multiple tasks.
- Most problematic aspect of CP was staying on painful feet and walking for extended periods - especially in less senior positions.
- Most Common Strategy was taking additional time at lunch or after work to build working stamina.

## Moderate CP: Employment

Broadly speaking CP Level 3 primarily uses a manual wheelchair.

- Most likely to have short term contracts or secondary roles.
- 60% had some level of additional funding support e.g. transport costs.
- Most common issues were transport and communication.
- Most effective strategy was planning additional funding ahead of time.

## Significant CP: Employment

Level 4 and 5 most commonly use a power chair or propelled manual chair.

- Were most likely to be self employed or in voluntary positions.
- 5% worked regularly for sustained periods of time.
- 50% found engagement with community activities such as Boccia.
- Support for the role in the form of personal care and adaptive equipment is crucial for success.
- Most common issue reported was communication.
- Effective strategy was recruiting for work assistants based on friend recommendations.

### PLAN FOR RESEARCH: MEMBERS RESEARCH DATABASE

A professional web site is planned that will allow members to search for specific categories of information including CP Level, Age, Education, Employment, Medical Issues, Mental Health, Ageing concerns, Personal Relationships, Access to support services as well as general CP information,



# Director Of Boccia

Boccia New Zealand is pleased to announce the appointment of Scott Martin as our new Director of Boccia.

Scott graduated from Auckland University of Technology with a Bachelor of Business and Sport and Recreation conjoint degree where he majored in finance and sport management.

He has had previous engagement with us as a contractor delivering our "Schools Boccia FUNdamentals" 2014 programmes to primary and secondary schools in the Central Auckland and Counties Manukau regions.



**Scott Martin**

Scott will now take up the role of Director of Boccia where initially he will work part time focussing on growing and sustaining participation numbers of players, coaches, officials and administrators. Other core responsibilities will include providing opportunities for improving club and school current practice and for strengthening their capability in delivering boccia programmes.

Scott has a passion for sport having been involved with it from a young age playing, coaching and supporting.

We welcome Scott to our Boccia team and look forward to working with him.

For further information contact [boccia@boccia.org.nz](mailto:boccia@boccia.org.nz)

## Abilities In Action Gym And Rehab

This Tauranga gym is becoming increasingly popular since it opened in 2012. The staff run specialised classes like neurological exercise programmes that help improve functional movements and sessions for middle aged and older adults that help reduce the risk of falling. There is also stretch exercise that help improve flexibility and functionality, low impact balance sessions that help improve standing, walking and even dancing and low impact exercises for spinal stabilisation. These exercises are designed to support the spine and surrounding muscles.

Also on offer are classes in Yoga, Strength sessions which focuses on large compound exercises, technique, strength and power and boxing. Yes wheelchair users pound away at the punching bag as the sessions also concentrate on technique, strength as well as conditioning.

The cost for these sessions is \$5.00 per class for gym members.

Abilities in Action Gym contacts are 14 Hocking Street, Tauranga, Phone (07) 5750105  
Free phone 0800 277 363



# Return To Work After The Ongoing Saga Of A Wheelchair Experience

Here I was again, nervously awaiting major foot surgery resulting from an unsuccessful procedure. I had done this before with both feet bandaged for 4 weeks so I knew my time in a wheelchair was to be challenging. Surgery was scheduled for December so I could recover over the Xmas break.

I didn't count on the overwhelming sense of abandonment, both my adult children abruptly moved to Australia and trusty friends who helped me last time were selling and moving from Auckland, or were away over Xmas. My house was not accessible. It was an impossible feat without the appropriate supports. Resigned to cancelling surgery, family outside of Auckland offered to support me through my convalescence.

## The Hospital Experience

Awaking from a wonderful unknown place but still induced with opiates, I was horrified to see at the end of the bed a big hunk of plaster hanging off the end of my leg "a cast" déjà vu hit me from my last surgery. "How was I going to manage 8 + weeks"? "house-bound" "will the family put up with me for that long"? At least they won't have to shower me, but still so dependent for everything else. Thoughts went rushing through my mind I felt vulnerable and such a nuisance to those having to care for me. And to add to my stress I had to decide what colour I wanted my cast.

Once I had calmed down, I texted my daughter in Aussie and said I had to choose a colour for my "cast" a few minutes later I received a very emotional, frantic call saying she was on line booking her tickets to fly home to be with me.



## Is that a nervous smile?

Obviously I was still under the influence of my opiate pain relief.

## The Flight Experience

Arriving at the airport with my purple cast, loaded with luggage, hand bag around my neck I was very grateful for the safety of having a wheelchair, it also provided me with a lap to stack smaller bags while juggling lap top and crutches on the bar between my good foot and knees. Now a pro at manoeuvring my loaned sports chair and forgetting it takes the skin off your knuckles through doorways just with the sheer speed of it, I was ready for my new experience with Air NZ.

With a roll of wheels I took off at a fearful speed heading down a small unseen grade leaning precariously to the left towards parked cars, luckily the shuttle lady was following with suitcase in hand, she broke into a gallop and ➡



grabbed the chair seconds before I wore my face on the door of a shiny black BMW "I hadn't taken third party insurance for that encounter." Just another lesson learnt (pack the wheelchair evenly.) Once tagged up and ready to go I was directed into a small taped off holding pen with others requiring assistance.

My trusty wheelchair driving instructor said "do not get out of the chair until on the tarmac" so I followed instructions. There I was waiting to be transferred onto an aisle chair which was purple to match my cast, then transported by a fork hoist with a little plastic house on it. Well what can I say! I felt like a real VIP and to make my day, the flight crew had purple uniforms.

## Earning my keep

If I knew how exhausting it was to do house work in a manual chair I would never have offered. Again bucket and mop balanced between my good foot and knees with the vac cleaning tube wrapped around my neck, I was ready for action, 3 hours later (normally take ½ hr) I was ready for a nana nap.

## Showering Experience

I daren't go into this most difficult experience it was not a pretty sight.

Again my humbling respect for those who challenge daily life in a wheelchair.

Would you like to be involved in research which will investigate ways of enhancing physical activity participation for people living with disability?

We are inviting adults living with chronic disability to participate in this study. Potential participants should not presently be engaged in regular physical activity, should be able to provide their own consent to participate, and live in Dunedin.

Participation in this study will enable you to see a physiotherapist 1-3 times who will help you participate in regular physical activity.

Should you wish to take part in this study and would like to see if you are eligible, please contact:

The School of Physiotherapy Clinical Research Administrator  
Email: [clinicalresearch.physio@otago.ac.nz](mailto:clinicalresearch.physio@otago.ac.nz)  
Tel: (03) 479 4979

This project has been reviewed and approved by the University of Otago Human Ethics Committee.  
Ref: H14/03



# TA iQ the New Standard



## What users have said:

The seat is so low, I can sit at a table, at my desk, drive a vehicle. At a cafe no one knows I am in a chair!

The iQ ride is so smooth, comfortable and fast.

All quality, no exposed wires, no visible control modules and real leather armrests.

## Why should you consider the TA iQ for funding?

1. A very low seat plate height of only 38cm / 15" reduces the need for customisation, sit under a table or drive a vehicle.
2. Excellent drive comfort, with independent suspension, no jolts over bumps.
3. Safer. Crash test compliance with ISO 10542-5 for restraint and docking, and ISO 7179-19 for use as a seat in a vehicle.
4. Cost effective, very sensibly priced, with all power options.
5. Available in MWD, RWD and FWD configurations.

## Compare the standard specifications



Seat height:  
Only 38cm / 15"



Suspension:  
More comfortable



Safer:  
Crash Test Approved



Higher:  
30cm / 12" elevation



Faster & Further:  
12.5 km/h, 40km

## TA Indoor equals superior indoor maneuverability

With a very small powerbase, 56cm wide and 69.5cm long, and a turning radius of only 45 cm ensures maneuverability in bathrooms, small spaces, and narrow doorways is a breeze.

Sit at any table with a very low standard hi-low seat plate height of 40cm.

Watch videos of the TA Indoor in action on our website:  
[www.mortonperry.co.nz/TA-Indoor-Powerchair.html](http://www.mortonperry.co.nz/TA-Indoor-Powerchair.html)

**Consult with your therapist**

***For further information or trials***

***Please contact us***



**Morton & Perry**  
Handicare Equipment Solutions

0800 238 423



[www.mortonperry.co.nz](http://www.mortonperry.co.nz)





# Upcoming Events

Due to unforeseen circumstances Janet has had to reschedule the following events. Please check below for new dates. Sorry for any inconvenience.

Attention Christchurch members

Note: Change of date now Saturday 1st August 2015

The "Funky Hot Mammals"

Chateau on the Park

The Funky Hot Mammals are described as two musical mistresses of mayhem. During this evening show, which includes dinner, this dynamic duo will perform feel good pops hits from the 1960's upwards. So bring along your dancing shoes/pump up your tyres to the max as the Funky Hot Mammals will rock your socks off. More details of this event will be supplied closer to the show.

## Also on the Christchurch Calendar

22nd November Sunday: Christchurch Christmas Lunch at the Orana Wildlife Park.

## Upcoming events

- 16th August Sunday: Waikato Lunch
- 13th December Sunday: Christmas Lunch at Eden Park, Auckland.

## Watch Out For Upcoming Events In August/September:

- Napier
- Wanganui
- New Plymouth
- Wellington
- Masterton
- Palmerston North

